

## **Question 6: How can we meet the needs of people with ASD as they progress into and through adulthood?**

**Aspirational Goal: All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, satisfying relationships, and meaningful access to services and supports.**

### **Introduction**

Each year in the United States, approximately 50,000 individuals with autism spectrum disorder (ASD) turn 18 years old.<sup>1</sup> According to 2016 Center for Disease Control (CDC) data, prevalence of ASD in eight-year-olds rose dramatically from 1 in 150 in 2002 to 1 in 68 in 2012.<sup>2</sup> The 2002 cohort is now 23 years of age. Thus, across the next decade, we can expect a 123% increase in the number of youth with ASD exiting secondary school. There are significant concerns about how this increase will affect the transition and adult disability service systems. Research to understand the unique needs of this growing population is urgently needed, in order to develop services and programs that facilitate opportunities for people on the autism spectrum to lead fulfilling, self-determined lives.

Since the *2013 IACC Strategic Plan Update*, there has been continued progress in understanding adult life for those on the autism spectrum. Nearly every study finds that adults with ASD have difficulty accessing disability and medical services, experience high rates of unemployment and underemployment, face difficulties in daily living skills and achieving independence, and contend with elevated rates of physical and mental health problems. However, we also know that *some* individuals with autism *do* experience positive outcomes. Little progress has been made in understanding how best to support these individuals and their families so good outcomes are the norm rather than the exception. This leaves providers and policy makers with an absence of evidence-based knowledge to use when deciding which services, supports, and programs will be most beneficial to adults with ASD, and few resources to implement those programs.

The increasingly influential voice of the self-advocacy community has highlighted the vast heterogeneity in strengths, impairments, and functioning among adults with ASD. Thus, real progress toward achieving the Aspirational Goal is even more challenging than previously thought, as it is highly unlikely that any given service, or program can effectively meet the needs of all adults with ASD. Yet, these same voices also highlight the many and varied ways that adults with ASD can make rich contributions to society, making it even more imperative to understand how to support them in achieving their highest potential.

It is important to note, that nearly every study cited in the following sections focuses on early adulthood and the transition years, and utilizes samples with little racial/ethnic or socioeconomic diversity. It is unclear to what extent these findings apply to individuals in mid- or later-adulthood, from racial/ethnic minority groups, or with fewer socioeconomic resources.

## **Section II: Progress in the field**

### **Transition to Adulthood**

The years immediately prior to the *2013 IACC Strategic Plan* update – from 2010 to 2013 – were instrumental to demonstrating the challenges faced by youth with ASD and their families during the transition out of secondary school and into adult life. Studies during this time demonstrated high rates of unemployment and underemployment,<sup>3,4</sup> difficulties accessing services<sup>5</sup>, disconnection from friendship and social activities,<sup>6</sup> and the negative impacts of secondary school exit on behavioral development.<sup>7</sup>

Pursuing postsecondary education can be important in fostering independence, self-determination, and employment success. Greater numbers of individuals with ASD are seeking higher education opportunities in vocational/technical skills, 2-year colleges, and 4-year colleges/universities.<sup>8,9</sup> Yet, fewer than half of college students with ASD feel they are able to handle most of the challenges they encounter.<sup>1</sup> The types of needed supports identified by individuals with ASD in higher education settings are not those typically provided by disability services, such as supports for living on campus or living independently, training to engage in self-advocacy, and interacting effectively with peers and instructors.<sup>10</sup> For students with ASD who have significant mental health concerns, intensive services addressing emotion regulation in addition to the organizational and social skills necessary for college success may be needed. For students with co-occurring intellectual disability, a college-like transition program with a focus on independent living skills may be appropriate.

Little has been published on issues related to community participation, such as housing, social participation, and community integration, have received since the *2013 IACC Strategic Plan* update. There is some evidence to suggest that youth with ASD tend to become more isolated from structured social/recreational activities in the community after leaving secondary school.<sup>11,12</sup> This may be problematic for many, as the presence of meaningful daytime activity is a key contributor to quality of life.<sup>13</sup> While no new data has been published on housing for people with ASD since the *2013 IACC Strategic Plan Update*, the most recent study found 87% of young adults with ASD lived with their parents or guardian after high school and only 19% had lived independently.<sup>14</sup>

There is a growing number of small treatment trials, funded through the National Institutes of Health, aimed at smoothing the transition process and improving adult outcomes for people with ASD. Targeted initiatives responsive to objectives in the previous IACC Strategic Plan are supporting many of these new interventions. Ongoing studies are testing programs to: improve transition planning in schools; train parents how to advocate more effectively for adult disability services<sup>15</sup>; improve family climate through group psychoeducational intervention<sup>16</sup>; target self-regulation and social competence among college students with ASD<sup>17</sup>; improve employment supports<sup>18</sup>; increase social skills<sup>19</sup>, and build job interviewing skills and customized employment supports.<sup>20,21</sup> Those interventions that show promising initial results ideally will be tested in large-scale randomized controlled trials, with the ultimate goal of incorporating them into treatment options to improve adult outcomes.

Despite these promising new directions for research, important gaps in knowledge remain. First, much of our information about the transition to adulthood comes from large, population-based studies such as the National Longitudinal Transition Study-2 (NLTS-2). These

studies have provided seminal information about the range and scope of needs of youth with ASD exiting secondary school in the United States. Yet, the measurement in these datasets does not have the detailed, personalized information needed to provide targeted recommendations to disability service workers on college campuses, parents who want their sons and daughters to succeed in college or employment, or adults themselves who are searching for the most appropriate services and supports based on their unique situations. Coupling high-level snapshots like the NLTS-2 with “deep-dive” data collection into the lives of adults with ASD of all ages will likely provide the best evidence about how to support these individuals. Furthermore, we could benefit from a close examination of research and services strategies that have been effective with other vulnerable youth (e.g., exiting foster care) and adult (e.g., those with severe mental illness) populations to identify policy and practice approaches that could be adapted for people on the autism spectrum.

Given the lack of evidence for specific ways to improve outcomes for youth and adults with ASD, paired with the high level of need, many publicly and privately funded initiatives are in place to improve post-secondary educational and employment participation and retention. College support programs for students with ASD are developing across the country, and college and universities without these programs consistently express a need for greater ASD-related support services. Yet, the effectiveness of these post-secondary education and employment programs is almost never evaluated. It is important to determine which of these many initiatives are producing positive results and for whom, so that an evidence base can be developed to guide service providers and policy makers as they are deciding which programs to implement.

Many of the cohort studies that inform our knowledge base about adult outcomes involve samples of individuals who were diagnosed with ASD 20, 30, or even 40 years ago.<sup>22,23,24</sup> With the many fast-moving initiatives around transition services and supports, community employment, and access to post-secondary education, it is unclear whether the post-school activities of youth with ASD who left secondary school 10 or more years ago are representative of today’s youth. Thus, it will be important to follow existing cohorts in the future, as well as continue to develop and follow new cohorts of youth with ASD as they transition to adulthood. This combination of strategies will allow us to understand development throughout adulthood, and ensure that recommendations for transition-related treatments and services do not reflect outdated needs of individuals and families.

### **Life Course Outcomes: Employment, Vocational Skills, and Community Integration**

Discoveries in the employment realm have centered on understanding patterns over time and the implications of formal services. For many people with ASD, maintaining work or post-secondary educational positions once they are obtained is a significant challenge.<sup>25,26</sup> Further, increasing access to vocational rehabilitation (VR) services for adults with ASD has not significantly improved employment outcomes across the last decade; only one-third of adults with ASD receiving VR services achieve successful employment.<sup>27</sup> These adults earned lower wages and worked fewer hours than other young adults with disabilities receiving services. Thus, even when receiving services, employment outcomes are poor for young adults with ASD. The few studies that have examined employment beyond young adulthood do not find patterns of improvement over time; most adults who are unemployed or underemployed in early adulthood tend to stay that way, and independence in vocational positions declines over time

for some.<sup>23,28</sup> It is important to note, however, that poor employment outcomes are not universal; some adults with ASD successfully obtain and maintain jobs. Little is known about the factors that distinguish those adults who have greater vs. fewer struggles with employment; those factors that have been identified are difficult or impossible to change, such as IQ or early language. One notable exception is self-care skills, which consistently predict employment and are amenable to intervention.<sup>3,28</sup> A wide variety of employment service options are needed, including current models of job finding and development services, long-term intensive services and supports, and long-term but minimal supports (e.g., a few hours/month).

There is almost no research on the community participation of adults with ASD in middle or later adulthood. The needs of individuals with ASD in terms of employment, housing, social participation and community integration almost certainly change as they age. Yet, evidence to support the development of targeted programs and support is woefully lacking. Families and corporations are leading the way in innovations to find and sustain meaningful employment and community housing for adults with ASD, but further research as well as state and federal government programs are needed to address current and future needs.

The heterogeneity of ASD symptoms and severity for those on the spectrum necessitates a variety of housing options to fit the specific service needs of each individual. Perhaps by virtue of the required infrastructure, housing options have been slow to respond to changing needs, values and research findings regarding adults with ASD. Lakin and colleagues (2008)<sup>29</sup> describe the national agenda to increase the number of community-based housing options for individuals with intellectual disabilities as a way of increasing community participation and self-determined choice making. The recent [final rule from CMS](#) gives clear preference to small, community-based homes over larger congregate care settings and intentional communities. Some advocates have hailed this ruling as a victory that will increase community participation; others, especially those who care for severely impaired and medically fragile individuals, have expressed grave concerns that appropriate care will not be available under this new financing arrangement. There are remarkably little data available to support which housing options work best for which individuals, with studies presenting contradictory findings regarding the level of community participation and choice making that individuals with ASD or ID have in different housing options.<sup>30,31</sup> Research is desperately needed on the most appropriate housing arrangements and in-home supports, and perhaps more importantly strategies to better observe what happens in these arrangements, to increase community engagement, and to maximize quality of life.

Longitudinal studies of adults with ASD remain rare, but those that have been conducted provide some suggestion that many adults move into and out of “successful outcomes” across adulthood.<sup>23,25,26,28</sup> To make progress toward the Aspirational Goal, there needs to be more focus on understanding how outcomes and needs of adults with ASD change over time, and how these variations compare to the general population. A one-dimensional look at outcomes such as vocation, health, illness, or quality of life at a specific point in time will not capture the rich diversity of life course trajectories. Further, it is almost certainly the case that interventions and programs to improve outcomes are more or less effective depending on when during adulthood they are delivered (right out of secondary school, for example, versus later in adulthood). However, we lack the basic, large-sample, descriptive studies to understand which types of interventions and services might be most effective for which adults, and when in the

life course they have the most influence.

Another barrier that slows progress in adult ASD research is the inadequacy of current measurement tools. Without valid, sensitive outcome measures, it becomes exponentially more difficult to detect whether an intervention or service is effective and should be pursued. Further, it may be necessary to reconsider indicators of outcome all together. Studies have typically defined what constitutes a “good outcome” (e.g., community employment, spending time with friends) and thus should be the target of services and supports. However, it is unknown whether these outcomes are the most meaningful to individuals with ASD or their families. It may be that the fit of the activities to the individuals’ interests and abilities is most important, or it may be that subjective quality of life should be an equal or greater focus as objective indicators like employment or post-secondary education. To reach the Aspirational Goal, careful research is needed to understand how to define “good” outcomes in a systematic yet personalized way, and then measurement tools are needed that reliably capture those outcomes. Once outcomes can be assessed in a way that takes into account the desires, skills, and abilities of adults with ASD and their families, then the Aspirational Goal of developing programs and supports that allow adults on the autism spectrum to reach those outcomes will be more feasible.

### **Health and healthcare**

Current knowledge about mental health, physical health, and healthcare experiences among adults with ASD is also limited. Psychiatric comorbidity (i.e., two or more mental health diagnoses co-occurring in an individual), known to be high among children and adolescents with ASD, remains challenging in adulthood. Most children with ASD who have other psychiatric disorders continue to have at least one comorbid diagnosis in adolescence and early adulthood.<sup>32</sup> More than half of adults with ASD have at least one additional psychiatric disorder, a rate that is considerably higher than in the general population.<sup>33</sup> Difficulties with mood and anxiety appear to be most problematic<sup>34,35,36</sup>, and failing to address mental health problems adequately can lead to poor outcomes. For example, individuals with ASD and mental health comorbidities are more likely to experience difficulties in adaptive functioning.<sup>37</sup> Even more sobering, recent research has indicated the rate of suicidality is estimated to be nine times higher among adults with ASD than in the general population.<sup>38</sup>

Co-occurring physical conditions are also a concern. Compared to adults without ASD, those with ASD have increased rates of common physical health conditions (such as: sleep disorders, gastrointestinal disorders, and diabetes), as well as rarer conditions (such as: stroke, Parkinson’s disease, and genetic disorders).<sup>33</sup> Children and adults with ASD in the United States have a higher risk of being overweight or obese than the general population, putting them at risk for cardiovascular disease, cancer and other chronic conditions across the life span. Outside of person-level factors such as gender, verbal ability, and ASD severity<sup>32,34</sup>, we know little about the full range of factors related to stability or emergence of co-occurring psychopathology among these adults. More work must be done to develop and test interventions that prevent, control, and/or moderate the effects of physical and mental health comorbidities.<sup>39</sup>

While adults with ASD experience increased rates of co-occurring physical conditions, individuals with ASD are at greater risk of injuries such as falls, suffocation, drowning, and self-

harm.<sup>40,47</sup> Unintentional injuries and wandering can often lead to premature mortality, citing a critical need for prevention programs targeting these risks.<sup>47</sup> Other health concerns related to safety, such as wandering and victimization, are discussed later in this chapter.

Studies on health care utilization indicate adults with ASD utilize a disproportionate amount of outpatient, in-patient, prescription, and emergency department services.<sup>30,40,41,42</sup> Only one study has examined self-reported utilization of preventive services, finding that adults with ASD were significantly less likely to report tetanus vaccination and pap (Papanicolaou) smears than adults without ASD.<sup>42</sup> Further, adults with ASD experience more barriers to service use and participation in the medical visit, as well as lower satisfaction.<sup>39,42,43</sup> Specific barriers include anxiety related to the medical visit, as well as unmet needs for additional time to process information and ask questions, additional modes of communication, and reduction of sensory stimulation.

Relatively little is known about the aging process in people with ASD and what types of interventions, services and supports might foster health maintenance as individuals age. Several studies have suggested that people on the autism spectrum are vulnerable to premature death due to a number of causes, including epilepsy, late diagnosis of medical conditions, and accidents.<sup>38,44,45,46,47</sup> More research is needed to understand causal and risk factors and develop strategies to prevent early death. In addition, research on how autism characteristics, comorbidities, and physical and social functioning change during the aging process will be needed to develop evidence-based practices to support the needs of people with ASD as they age. We anticipate that the needs of those who are currently older adults, who may not have received interventions and services earlier in life, may also be different from the needs of current youth and young adults who received different types of interventions and services in the period before reaching adulthood.<sup>48</sup> Thus, research on current older adults with ASD and longitudinal research to follow the trajectories of youth and young adults will both be necessary to meet the needs of the population of adults with ASD.<sup>49,50</sup>

Although there is a reasonably good understanding of the prevalence and disparities in various health states for adults with ASD, there are several gaps in this knowledge base, including how best to screen for and clinically assess secondary conditions and monitor progress, as well as treatment dissemination and provider training.<sup>23,51</sup> There have been few attempts to establish the validity of instruments commonly used to assess other psychiatric conditions in individuals with ASD. There has also been limited consideration of differences in how the manifestations, course, or treatment of psychiatric disorders might differ for these adults. Further, the majority of studies on physical health needs of adults with ASD utilize retrospective point-in-time data and lack objective health assessment measures. Better measurement tools and methods are necessary to understand the scope of physical and mental health needs and design appropriate services and supports.

Research involving adults with ASD clearly show that they desire and are often capable of more independent management of their health.<sup>42,52</sup> To ensure these adults are able to participate in their care to their fullest abilities, the health care system must increase health professionals' knowledge about ASD in general and risk factors for co-occurring conditions. Similar to the general population, providers should examine the adult's general physical and mental health needs and provide guidance on how to ensure the person is living the healthiest and highest quality of life possible. Small adjustments to the clinic setting (e.g., preparatory

written\verbal communication about visit procedures, private waiting rooms, use of alternative forms of communication, care coordination and extended time) can greatly improve the health care experience, compliance, and involvement for adults with ASD. Previous initiatives to improve care for those with ASD in the United States have fallen short in allocating funding and provide little guidance regarding appropriate care for this population.

### **Adult diagnosis**

Longitudinal studies demonstrate clear evidence that ASD-related difficulties persist well into adulthood. In several cohorts of children diagnosed with ASD in early childhood, 80-90% of individuals continued to meet criteria for clinical diagnoses of ASD as adults.<sup>53,54</sup> Simultaneously, increasing numbers of adults are presenting to clinics for first time diagnoses, and recent epidemiological work suggests that many adults with ASD may be unidentified and living in the community without appropriate supports.<sup>55</sup> In addition, as development of screening and diagnostic tools, as well as other autism research, has largely been accomplished using data from boys and men, girls and women on the autism spectrum may be underdiagnosed, and we know little about their ASD trajectories across the lifespan.<sup>33,56,57</sup>

Research to improve adult diagnosis is very new and, as such, there are many important gaps and areas for future study. First, there is limited knowledge of the manifestations of ASD in adults. Longitudinal studies have found that some adults with ASD show “improvement” in autism severity compared to estimates obtained during earlier childhood or young adulthood.<sup>23,58,59</sup> However, an extensive body of child research has shown that ASD symptoms differ depending on a child’s developmental stage (i.e., language and cognitive abilities, as well as chronological age), and the types of behaviors that best differentiate children from neurotypical peers are somewhat different from behaviors that differentiate adults with ASD from neurotypical peers.<sup>60,61</sup> Thus, apparent “decreases” in autistic characteristics may simply reflect that instruments designed for use with children do not adequately query the types of behaviors or deficits most relevant to adults with ASD. Currently, there is not a standard tool or measurement used for diagnosing ASD in adults. However, there is an ongoing study to adapt the Autism Diagnostic Observation Schedule-2 (ADOS-2) Module 4 for use in diagnosing adults.<sup>61,62</sup> There is also hope that work being done to create biomarkers that predict ASD, such as perceptual computing measurements of quantitative traits, will be able to be adapted as tools for diagnosing adults as well.<sup>63</sup> Research is needed to understand how ASD symptoms change across development and how core deficits manifest in adults. Studies must include consideration of young, middle-aged and older adults, including those diagnosed as children and those identified in later life.

Second, little is known about individuals who obtain first-time ASD diagnoses as adults. Many of these adults have other mental health concerns; in one study of young adults seeking a first time ASD diagnosis, 46% had a previous psychiatric diagnosis, and 53% had contact with mental health services.<sup>64</sup> These findings suggest that a population of individuals with high needs is being misdiagnosed or “missed” as children. Research is needed to understand profiles of strengths and challenges of this population, to inform development of screening and diagnostic tools and best diagnostic practices for adult ASD referrals. Such research will need to take into account that adult psychiatric assessment traditionally relies on self-report, whereas ASD diagnostic practices rely more on direct observation in structured clinical settings and/or

caregiver report. Childhood caregivers may not be available or may have difficulty recalling specific behaviors occurring many decades ago. Exclusive reliance on self-report may also not be ideal, due to possible limitations in insight, communicative difficulties, or over-reporting of symptoms to achieve secondary gain (e.g., involvement in legal system, to obtain financial assistance).

Third, currently it is not known if and how later-life diagnosis affects mental health or well-being, or fosters identification of supports or interventions. Considering that state-funded support programs often require documentation of diagnosis prior to 18 or 22 years of age, it is unlikely that someone diagnosed in middle adulthood would be able to access ASD-related supports. Obtaining a diagnosis in the absence of appropriate services and supports may be detrimental to well-being for some individuals. On the other hand, they may benefit from private services, participation in online communities for individuals with ASD, etc. Research in this area is needed to educate adults self-referring for diagnosis about the possible benefits and risks of obtaining an ASD diagnosis, as well as to provide insights into the types of services that should be developed to support the adult's integration of diagnosis into their self-perceptions.

### **Service Delivery for Adults**

As the research base continues to build, there are improvements in service delivery that can be made to reach the Aspirational Goal more quickly. First, it is critical that additional funding is provided for adult disability services. Currently, waiting lists for services in most states are very long, and adults with ASD rarely receive the range and extent of services that would allow them to reach their potential. Adults with ASD and their families who are more vulnerable to poor outcomes in adulthood – by virtue of having fewer socioeconomic resources or being of a racial/ethnic minority group – also have the greatest difficulty accessing needed services.<sup>3,65</sup> It will be nearly impossible to reach the Aspirational Goal of self-determination, choice, and meaningful access to services – especially for those who are most vulnerable – without a significant investment in the quantity and quality of adult disability services and actively working to reduce barriers to access.

One way to increase quality is to invest more in the training of professionals, across disciplines, to work effectively with adults with ASD. Few adult care providers (healthcare, mental health, employment supports, etc.) have received training on how to support adults with ASD. The implications of this lack of training are far-reaching. Staff turnover is a significant issue in vocational and residential support services, and likely stems (at least in part) from inadequate training. Many adults with ASD receive their health care in pediatric settings, due to a dearth of adult providers who feel competent and comfortable treating them. This can pose a health risk, as pediatric providers are not trained to treat adult health issues. In terms of diagnostic issues, few validated screening and diagnostic instruments are available for use in identification of ASD in adults, and few clinicians specializing in adult screening and diagnosis are available to provide services. Neither Psychology nor Psychiatry educational programs (as well as other disciplines) are adequately preparing trainees to diagnose adults with ASD. The few programs that offer clinical rotations through specialty clinics often focus on persons under the age of 18 or 22, due to their presence in pediatric departments. As such, there is a need for training grants and initiatives focused on training professionals who will be working with adults to detect, diagnose, and address mental and physical health-related needs in this population.



Progress will be achieved more quickly if greater focus is placed on the coordination of services between states, between agencies that provide adult services, and between school-based and adult services. Currently, Medicaid-funded services do not transfer between states, limiting people's mobility when relocation to another state would serve them well. Given that most adults with autism have complex needs that bring them into contact with multiple public service systems, there is an urgent need for research and initiatives focused on care coordination, interagency collaboration, strategies for integrating extant funding streams, and community-based collective impact strategies. [The 2014 Workforce Innovation and Opportunity Act \(WIOA\)](#) specifies that state VR agencies must set aside 15% of their funding to provide transition services to secondary school students. However, it remains to be seen if state agencies will be able to carry out the responsibilities associated with legislation such as WIOA. It will be important to monitor the effectiveness of these initiatives with careful data collection and analyses. Also, WIOA is designed to encourage state-level experimentation and variability in program design. This presents a unique opportunity to study emerging practices and capitalize on this variability to learn what works for whom.

### **Safety, Victimization, and Interactions with Law Enforcement**

In the past five years, safety issues have emerged as a key concern in the autism spectrum community, yet the research evidence on this topic has lagged far behind. Although not yet examined in adults, elopement and peer victimization (social, verbal, and physical) are common in children and adolescents with ASD.<sup>66,67</sup> A recent report suggested that, relative to adults in the general population, adults with ASD were twice as likely to experience sexual coercion or rape.<sup>68</sup> While there has been insufficient evidence, there is some suggestion that adults on the autism spectrum might more often be involved in the criminal justice system, recent data from the NLTS-2 suggests that transition-aged youth with ASD were actually less likely than those with other disabilities to be stopped by police or arrested.<sup>69</sup> Although, it might be that when they are engaged with police, impairments related to ASD make those interactions more difficult, leading to negative outcomes.

Careful research is needed to understand the experiences of victimization in adulthood – sexual victimization, physical victimization, and being taken advantage of – as well as the prevalence of other safety risks, such as wandering and the often adverse outcomes that unfold from wandering. While little is known about adults with ASD wandering behaviors, a recent report found 27% of adolescents engaged in wandering behavior within the past year.<sup>9</sup> Wandering from safe places and situations can lead to individuals with ASD being lost, missing, or injured. Studies are needed to understand the characteristics of those adults whose safety is at risk, so that preventative efforts can be put into place. Research focused on adults in the criminal justice system are also important to understand precipitating factors for criminality or adverse interactions with law enforcement; Helverschou et al. (2015)<sup>70</sup> found that among criminal offenders with ASD in Norway, 67% of crimes were related to obsessions or special interest. A recent study assessing the experiences of adults with ASD and police officers in England showed conflicting views on the quality of the interaction<sup>71</sup>; police officers expressed satisfaction with how they had worked with individuals with ASD, whereas the individuals with ASD were largely dissatisfied with their experience of the police. Research strategies to develop

a better understanding among law enforcement might lead to less adverse interactions and result in treatment rather than incarceration, which does not improve the situation for people with disabilities. Long-term studies should also examine the impact of childhood victimization or other threats to safety, as these might lead to mental health problems among adults with ASD.<sup>72</sup> Intervention studies to improve awareness and safety are necessary.

There are currently a limited number of programs to improve safety for individuals with ASD. In some communities, police officers and judges receive training on autism spectrum features, so that impairments associated with ASD are appropriately considered in interactions. Despite this, the current research is insufficient to understand the types and extent of need, or to inform evidence-based programs to ensure safety among adults on the autism spectrum.

### **Long Term and Caregiver Supports**

One of the best understood predictors of outcomes in adulthood is level of cognitive functioning: relative to those with ASD without an intellectual disability, adults with ASD who have an intellectual disability are significantly less likely to be employed or living in the community (e.g., Howlin & Magiati, 2017<sup>73</sup>). However, little is known about how to support adults with ASD and co-occurring intellectual disability in reaching their maximum potential.

More work is needed to understand and evaluate the effectiveness of long-term supports for those with high support needs (such as those with significant cognitive impairments). As many of these adults will be receiving some sort of formal adult disability service, more rapid headway can be made in this area if service providers systematically collect outcome data. As with other areas, the results will not be one-size-fits-all: the most appropriate supports will depend on the skills and desires of the adult, as well as the specific area being targeted (e.g., vocational skills versus mental health). Supports should also take a lifespan developmental perspective, encouraging the development of new skills and abilities throughout adulthood. For those adults with difficulty communicating, parents and other care providers can play a key role in relaying their sons' and daughters' preferences and interests. Person Centered Planning tools such as PATHs<sup>74</sup> and MAPs<sup>75</sup> can be useful to incorporate the perspectives of adults with ASD with more significant impairments.

Further, the knowledge base about how to support individuals with ASD as they move into middle and later adulthood is almost non-existent. Small-sample studies have provided some suggestion that needed supports will likely intensify in old age; relative to typically-developing controls, older adults with ASD experienced more severe cognitive declines in some domains and higher frequency of Parkinsonism.<sup>76,77</sup> Housing needs will surely intensify when parents are no longer able to provide care.

Often families play a critical role in providing support to their adult sons and daughters on the autism spectrum. Once youth with ASD leave the school system, responsibility for finding and coordinating services tends to fall to parents and siblings. In many cases, adults with ASD continue to live with their parents until parents are no longer able to care for them. Even when adults live independently or semi-independently, parents often provide supports (e.g., financial, tangible) that facilitate the son or daughter remaining in that residential situation. For adults who are better integrated into their communities, family burden is often significant as they tend to be responsible for coordinating/organizing activities.<sup>11,78</sup> Exceedingly high levels of stress among parents of adults with ASD have been found via self-report measures as well as

biological indicators of stress (e.g., cortisol<sup>79</sup>). However, there are few interventions aimed at supporting families. Most parent-focused interventions, when their children with ASD are adults, provide caregivers with skills or knowledge to better support their sons and daughters, and not necessarily to improve their own stress and well-being.<sup>15,16</sup>

Despite the prominent role of families in the lives of their adult sons and daughters with ASD, their influence is often ignored in research. There is a significant research gap in understanding which families are most effective in supporting their adult offspring with ASD, as well as in how to provide services and supports so that families can continue to provide care.<sup>80</sup> These research questions become even more important in the face of an underfunded adult service system. Because housing and other adult services are limited in availability, it is even more critical for policy makers and providers to ensure that families are well-supported so that they can continue their caregiving role as long as possible.

### **Section III: Overall Progress towards Aspirational Goal**

To understand how to support adults with ASD, it is first necessary to investigate the specific areas in which adults might need supports. This is, perhaps, where the greatest progress toward the Aspirational Goal has been made. We have reasonably strong evidence about the struggles faced by adults with ASD in acquiring needed disability services, accessing health care, finding appropriate employment or vocational activities, and achieving good mental health – at least during young adulthood.<sup>3,5,24,34,37,81</sup> Yet beyond basic description, there are numerous gaps in knowledge that limit our ability to support these adults effectively. The vast majority of what is known about autism spectrum disorders in adulthood has come from samples of primarily white, middle-class, well-resourced families of males with ASD who are of average or above average intellectual functioning. It is unclear how much of our current knowledge about how to achieve the Aspirational Goal would translate to those adults and families who are under-represented in research. Thus, studies should focus on including more diverse participants, including families with low socio-economic resources, youth and adults with severe intellectual impairment, those who are of racial/ethnic minorities, and women on the autism spectrum.

It is unlikely that we will make meaningful progress toward the Aspirational Goal without substantially increasing funding for adult autism research and services. **Research focused on adult issues has lagged far behind other types of ASD-related research, comprising only 2% of all autism research spending in 2015.**<sup>82</sup> Many fundamental questions about the life course that are unanswered among adults with ASD – such as basic understandings of how core and related symptoms, functional outcomes (e.g., employment, education, independent living), and health change across adulthood, along with the variable factors that predict improving life course trajectories and quality of life – have been well-researched in other groups and conditions. These questions form the necessary building blocks for effective and efficient interventions and services, nevertheless, these questions can be seen as lacking significance or innovation for those outside the autism field (who assume the answers are known). This can be a significant barrier when attempting to obtain funding for adult autism research. We will make more rapid progress toward realizing the Aspiration Goal once it is clear that a range of studies – from understanding biological and cognitive processes underlying outcomes, to more “natural history” studies of the life course, to evaluating existing services, to intervention trials to

improve outcomes – are critical to support adults with ASD in reaching their maximum potential.

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## **Objectives**

### **Objective 1: Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.**

- Use population-level data to understand unmet needs, disparities in access and outcomes, emerging usage trends, cost issues and the effectiveness of services in achieving their desired outcomes.
- Conduct research to determine the prevalence of autism in adults and the scope and distribution of service needs among the population to inform policy and program planning.
- Develop strategies for reducing socio-economic or racial/ethnic disparities in service access and related outcomes for adults with ASD.
- Investigate social capital, the network of supports, and community integration provided by families, service providers, and others to understand the range of formal and informal supports needed to achieve successful adult outcomes.
- Develop additional service coordination across agencies (e.g., educational and vocational rehabilitation; mental health and vocational rehabilitation).

### **Objective 2: Support research and implement approaches to reduce disabling co-occurring physical and mental health conditions in adults with ASD, with the goal of improving safety, reducing premature mortality, and enhancing quality of life.**

- Conduct large-scale longitudinal studies across adulthood into older age to examine trajectories of physical and mental health conditions, and address the additive and interactive effects of biological, cognitive, behavioral, and environmental factors that lead to co-occurring conditions.
- Conduct studies of approaches to treatments to reduce mental health conditions, including anxiety, depression, and/or suicidality.
- Engage adults on the autism spectrum and their families, through collaborative and participatory research, to be involved in the development of ecologically valid measures of quality of life, which can be used to understand the factors associated with positive quality of life throughout adulthood.
- Create programs to recruit and train more general physical and mental health providers to be knowledgeable about and willing to treat adults with ASD. This applies to primary care providers, community mental health providers as well as specialists.

### **Objective 3: Support research, services activities, and outreach efforts that facilitate and incorporate acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum into society.**

- Examine factors and support strategies that promote successful participation and retention in post-secondary education, employment, and/or community living activities across the spectrum of ASD and across the adult lifespan.
- Develop reliable outcome measures that take into account the desires of the individual and his/her family, as well as the match of the activity with the interests, skills, and

abilities of the adult.

- Conduct long-term follow-up studies examining the effects of interventions and services delivered in childhood on later adult outcomes.
- Conduct large-scale studies of programs to improve the skills that may underlie many aspects of community integration (e.g., adaptive behavior, executive function)
- Better understand the needs of adult service providers, as well as the characteristics of effective providers.
- Encourage more skilled workers to enter and remain in the adult disability service provider field, which is critical to improving self-determination of adults with ASD.

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